<u>Concurrent Session One – Data Collection, Reporting, and Quality Assurance</u>

Tim Quinn
Facilitator
CDC/PPB

Tim Quinn called the session to order. He explained the purpose and the format of the session, and then introduced the panel members who delivered overview presentations, and/or engaged in deliberations with the participants.

Choi Wan
CDC/PERB
CDC Representative

Choi Wan gave a background presentation on data collection, quality assurance, and data reporting. He explained that evaluation data is divided into three major types:

❑   Quality of interventions being provided by CDC Heath Department grantees
❑   Characteristics of clients targeted and reached by interventions
❑   Effects of interventions on client behavior and HIV transmission

There is a conceptual framework for the Evaluation Guidance, and different components of the framework correspond to different evaluation activities. Some of the components are not required, for instance, for this funding mechanism, outcome monitoring is not required. Each evaluation activity requires a different data collection process, and therefore a different strategy, even within a single jurisdiction.

CDC envisions the ERAS system acting as the reporting system for health departments. He expressed his hope that the system would reduce and ease their paperwork load as well as improve the quality of their reporting. The ERAS system will be available for health departments to use free of charge.

He said that another way to look at evaluation processes is to examine the data flow from the client level to the interventions to the provider to the health department to the CDC. In thinking about data collection procedures, Choi Wan urged the group to think about quality assurance procedures at each step in the data flow. Quality assurance (QA) includes accuracy as well as quality of the reported data. This point is important in understanding the effectiveness of HIV prevention efforts conducted by jurisdictions. Quality assurance has to be an ongoing activity with data reporting sources. The ERAS provides validation, but quality assurance goes beyond

the ERAS system, as each part of the data flow must incorporate quality assurance measures. He noted that training staff at all levels will help to ensure quality.

Winifred King
CDC/CBB
CDC Representative

Winifred King, of the Science and Application Team, described available technical assistance (TA) resources as being:

❏   NASTAD, which offers peer-to-peer technical assistance for health departments;

❏   MACRO, which can provide TA to the states; and

❏   CDC, which offers TA to the states via the Science Application Team and the Program Evaluation and Research Branch.

If TA is needed, Winifred King pointed out that the first step is to call the Project Officer, who will contact the Science Application Team to handle the request. Types of available TA include:

❏   Interpretation of the Health Department Evaluation Guidance
❏   Ways to ascertain the scientific basis of prevention programs
❏   Process monitoring and process evaluation
❏   Outcome monitoring and outcome evaluation
❏   Data collection and management procedures
❏   Strategies to improve quality assurance

Available TA is not limited to that list, she assured the group. There are, however, limitations to how CDC can assist health departments. These limitations are due to limited staff resources and other reasons:

❏   CDC cannot do the evaluation for the health department
❏   CDC cannot analyze data from individual states
❏   CDC cannot come to a state and conduct basic training on the Evaluation Guidance

She indicated that CDC will offer national training sessions on evaluation to health departments and CBO's.

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Hope Cassidy-Stewart
State of Maryland Health Department
Maryland's Data Collection, Reporting, and Quality Assurance

Hope Cassidy-Steward indicated that before the Evaluation Guidance, the Maryland Health Department ran monthly and quarterly aggregate data collection for all of their intervention types. Hard copies were mailed to the Department, where they were aggregated and then sent to the CDC. The data was not meaningful, however, because many of the numbers were estimates. July 1, 2000, marked the beginning of the first year of implementing process monitoring in the state of Maryland. This process involved data collection tools tailored by intervention type, intervention forms, participant forms, sign-in sheets, and centralized data entry, analysis, and reporting. Maryland processes all of the data and reports it to its vendors.

Their two goals for their system were:

❏   Valid information
❏   Standardized information

For valid information, she said they wanted client-level data, including age, race, demographics, and risk. Self-reported data was preferable, when possible, to avoid relying on the perceptions of facilitators. They hoped to create an accurate picture of HIV prevention in Maryland. Across the state, data should be collected in the same way so that the health department could compare information from different projects in different settings to create baseline data for evaluations and future comparisons.

Data collection instruments are client-level for all interventions, except for public information that comes from sources such as health fairs. The data includes self-reported demographics and risk information, when possible and appropriate. The health department had hoped for a single data collection tool that could be used all over the state, in every intervention, but they learned early on that different intervention types mean that different levels of specificity and information are feasible.

Hope Cassidy-Stewart said that ILI and GLI, the more intensive, skills-based interventions, use participant forms in English and Spanish. They include self-reported demographics and risk and are confidential. For health communication sessions, they use sign-in sheets, which capture some demographic information. Across their interventions, they use intervention forms to look at content. The facilitator completes the form, which tries to capture the context in which clients are being reached. For outreach activities, there is an outreach form, which is a grid that workers can take into the field and note after their encounters such information as perceived risk, the content of intervention, whether a referral was made, and the distribution of prevention devices

or materials. The area of prevention case management, counseling, and testing, has forms and procedures that they have been using for years, and they are still using them.

A year before implementing the evaluation guidelines, health department staff began to devise how to develop the instruments. Some of their challenges included:

❏   The instruments have to be used across the state, in diverse settings, with diverse intervention types;

❏   Collecting sensitive risk information and the accompanying concerns about confidentiality; and

❏   The dramatic change from the previous data collection system.

After the health department staff created a list of needs for the data collection system, they created drafts of systems and piloted them across the state, in different settings and with different interventions in different target populations. They sought feedback from both the facilitators and the actual participants. Based on this feedback, the revised forms were implemented on July 1st. Six months later, they conducted an assessment that included site visits, interviews, and collection of more feedback. They have just completed the revision of their forms for the second year.

Confidentiality was a big concern among vendors and participants, she said. Participant forms that collect risk information are only used in more intensive interventions. In Maryland, youth under fourteen cannot answer these questions, and some school-based settings prohibit those questions as well. The forms are anonymous and put in sealed envelopes. They conducted statewide training sessions before the first year of implementing the system. The first year was still very difficult. Not all vendors complied with the new system, the data quality was not consistent, and vendors are still not all "on board." They have enforced the importance of completing the forms, though, and they have conducted updated training sessions.

The new data collection systems represent a big change for contractors, and they met with a great deal of resistance. In their state, their vendors have become very interested in the content of the forms. They are very active and vocal in training sessions, which indicates their interest in getting the system right. Their biggest challenge has been to create instruments that work in a variety of settings, that make everyone happy, and that collect the kind of statewide data that they can use. She was heartened by the vendors' engagement in the process.

The health department aggregates the data and then sends it back to the vendors, she said. On a monthly basis, they send a summary to the vendors, internal managers, the state legislature, and CDC. One of their biggest goals for their system is to make the information accessible and to

actively contribute to program improvement. They compare the results with the design, working with individual vendors to understand the importance of the information and see its value in their day-to-day operation.

At this stage of their instrument, quality assurance is the most difficult aspect. In the first year of the system, they understand that the quality of their data is not very high. The information is more accurate every month as more vendors report. One of the reasons they do centralized data entry is to monitor the quality of the data in the first years. Their vendors vary in technical capacities, so the health department can work closely with them. Site visits are a part of their system, as it is important to ensure that the forms are being used appropriately and that they are being used quickly and accurately. In conclusion, she noted that copies of the instruments would be available at the swap meet.

Tim Quinn thanked the presenters, then broke the large group into three smaller groups. Each attendee was asked to write his or her most pressing question about data collection on a 3 x 5 index card. Then, in the smaller groups, they discussed the questions. A listing of each group's notes follows:

Group One Notes

❏   How do you make a data collection form that vendors will understand and use properly?

➡   Involve them in the process

❏   How do you motivate CBOs to collect the data you want? What kind of incentives could be offered?

➡   Funds
➡   Feedback
➡   Highlighting folks

❏   Providers/vendors do not understand: 1) the difference between number of interventions the form covers and number of clients or contacts (these numbers are not the same); 2) how to complete Hispanic/not Hispanic and then do race tablets.

➡   One-on-one TA with CBOs

❏   Garbage in garbage out: quality of local data collection, quality when aggregating data, steps that need to be taken to "raise the bar" or "kick it up a notch."

➡   Start with RFP elements to address QA specific, constant communication

     demystifying the whole process
➡️   Pay attention to how you communicate data back to contractors

❑   How to retain client confidentiality in rural areas with small numbers of clients:

➡️   In extremely small cities tell contractors not to collect data that would compromise confidentiality
➡️   Consider your system to see who sees data direct submission or through several layers

❑   How do we best do training and provide TA on our new web-based system?

❑   Suggestions for improving: CBO and local HD staff having basic computer/data system skills:

➡️   This is difficult often because of turnover/low pay/lack of skills
➡️   Look to see if you have a trained pool available
➡️   Never train just one person in an agency
➡️   Internal state systems have training available, can contracted people sit in on these

❑   Does anyone have experience with unique identification numbers for clients in order to un-duplicate clients served by more than one contractor or the same contractor over time?

➡️   HIV and name to code system in Montana
➡️   In California, tracking referrals use matching criteria like DOB and gender
➡️   Clients don't have problem usually it's the advocate who resists collection of coded information

❑   How do we validate required data to contractors for buy-in?

➡️   Timing the question back to the field staff and ask how it can be good for them – why is it used?
➡️   Use data for grant-writing purposes
➡️   Make it part of RFP process
➡️   TA on how to collect data (site visits)

❑   How do we market the evaluation system, especially the forms to get everybody to use them and get information that reflects quantity and quality?

➡ Contractor specifically focused on evaluation. Ready to respond and meet individually with contractors

➡ Contractor very community-friendly could relate to CBO's

➡ Road show around state trying to discuss with CBO's what they do/need

➡ Connect researchers with CBO's through local universities

➡ Do site visits to CBO's

❏ How do we minimize the time spent collecting and reporting data (and receiving data) and still maintain good quality/reliable information?

➡ Clerical staff can enter basic data for aggregate data

➡ Maine reports go through clerical staff, then data manager – demographic/ narrative reports with time-lines, documented written protocol

➡ TA and data management at CBO's can simplify data

➡ Provide CBO's TA on data collection/spreadsheets

❏ What would be the minimum requirements for program monitoring? In small states with small programs, it's difficult to implement elaborate processes due to minimal staff available to carry out the workload.

➡ CDC example of how western states utilized contract to do monitoring

➡ Do the best you can with what you have

➡ Data can be submitted in various ways (i.e. process don't get caught up in format)

❏ Training of agency members for data collection – how to fill out the data forms and getting agencies to do it:

➡ Don't pay subcontractors without forms properly completed – "form doesn't arrive, check doesn't go out"

➡ Web-based training to help

❏ How can we get an accurate number and picture of individuals served during HERR activities? (i.e. usually collect data based on CP6 and CDC needs). If we get questions that deviate from that hard to answer for education, outreach?

➡ Aggregate data can accomplish the evaluation need

➡ Don't necessarily need individual data

Group Two Notes

❏   How do we translate our data into those nifty CDC three-way tables?

❏   How do we develop a simple, not time-consuming, user-friendly, data collection form which captures required data for CDC plus risk behavior?

❏   Sufficient capacity (HD and CBO) to initiate process for data collection/instrument development.

❏   CBO-level understanding of how their existing programs/interventions relate to the evaluation guidance and the impact of confusion on how data is entered. NOTE: we have an extensive electronic system already in place.

❏   Federated state of Micronesia – no data collection (standardized system in place) – lack of resources (instrument, form) database.

❏   We are in our second year of using newly created forms for collecting data on small group sessions. Problem: CBO translation and use of sign-in sheets in a consistent way so that information is translated correctly – sometimes don't use one sheet.

❏   What are the "best practices" being implemented at the provider level – instruments and methods for collecting data?

❏   Must every state "re-invent the wheel?"

❏   What are some strategies for quality assurance in data collection and reporting?

❏   What are some ways to smooth the transition for vendors from group-level aggregate data to client-level data for GLI's ILI's?

❏   How do we conduct data collection on a shoe-string budget?

❏   Will CDC provide the software for a web-based reporting system and assist HD in the installation of the system?

       ➥   6 - 9 months
       ➥   Referred to data management system
       ➥   Don't standardize

❏   Will CDC fund a position specific for data collection? Without a position, this task would face numerous challenges/barriers related to data reporting (i.e. reporting, implementation, etc.?).

➡️   HD can hire someone

❏   How do we collect data on GLI # sessions?

     ➡️   NY responds

Group Three Notes

❏   What it takes to get started – methodology/spreadsheet:

     ➡️   Engaging stakeholders in the planning process, achieve buy-in from those collecting the data from the field. Encourage stakeholders to provide input into what type of data will be collected (bring all stakeholders together)

     ➡️   Need to clarify <u>purpose</u> of data. What the data will be used for helps determine what type of data to collect

     ➡️   Is it possible to collect the data? Attempt to tailor data.

     ➡️   Why should <u>specific</u> data be collected?

     ➡️   Look at existing evaluation tools to avoid duplication in the jurisdiction – who is already collecting similar data locally, within, and across states

     ➡️   Look at what you've done.

     ➡️   Need to establish <u>key</u> data collectors for each organization and establish working relationships.

     ➡️   Ensure data forms get to the HD.

     ➡️   Pilot test tools/train staff to ensure stakeholders understand the instrument.

❏   Reporting: how do we collect data w/o overburdening the contractors?

     ➡️   Is Web-based reporting the answer for CBO's?

     ➡️   CDC or independent jurisdiction WB systems? Hope CDC will get Web-based system up and running ASAP

❏   If using an independent system, it should interface with the forthcoming CDC WB system, ERAS:

     ➡️   Want to utilize a Web system for reporting so data won't seem so overwhelming for providers and vendors.

     ➡️   Seeking uniformity, yet flexibility for states

     ➡️   Optional fields

     ➡️   Individual versus aggregate data for output

❏   How does one collect individual-level data for outreach or is it recommended/useful?

➡   Many do not see value in collecting client-level data (comprehensive info. on individual)
➡   Instead <u>lump</u> characteristics of targeted population in aggregate form
➡   Attempt to collect clean data as best you can (it's the quality of the data – what level of quality is OK?)
➡   Discretion of outreach workers is very valuable
➡   Guam – differed with opinion above due to varied value systems and different populations
➡   Familiarity is key to success
➡   Translation process takes time
➡   Letting RFPs cause significant delays in reporting – CDC needs to understand barriers
➡   CDC changes have tremendous effect on local jurisdictions translating amendments to contractors: when CDC changes definitions, e.g. race/ethnicity, it creates challenges for HD as they work with their vendors to explain the change or new requirements. Often means re-training providers/vendors. Changes have to come in time slots for the HD.

❏   How do we collect race/ethnicity data and be OMB-15 compliant? Also, be understood by state/Fed?

➡   Hardest part is getting data collectors to collect race and ethnicity separately
➡   OMB-15 has many sub-categories identifying race/ethnicity

❏   How can HD assess the accuracy and QA of data collected?

➡   Continuous communication and training with providers – address FAQ
➡   Set goals for completion of data
➡   Must reaffirm to vendors that they will experience change in numbers – this is to help them with the fear factor of not being refunded
➡   Data should not <u>purely</u> be numbers driven; grantor needs to let contractors know due to additional evaluation requirements they will understand if objectives are not met fully (i.e. 500 vs. 560 persons) due to implementation of evaluation requirements
➡   Have a clear understanding that service provision is important and if agencies are not doing what is required, they could lose funding if objectives are not achieved (this must be stressed to vendors and put in writing)
➡   Because of paradigm shift with evaluation guidance – HD must work closely with vendors/providers to keep them trained and informed

➜   Capacity-building is <u>key</u> – must have mechanism in place for consistent training and skills-building

➜   Efficient and easy to use, must have user-friendly data collection systems

❏   Does the state need a programmer to assist with data collection needs and activities?